

Autism Spectrum Disorders: Screening and Referral Trends among Connecticut Pediatricians

Student Investigator: Christine Raymond RN, LEND fellow

Principle Investigators:

Mary Beth Bruder PhD
& Robert Greenstein MD



A.J. Pappanikou Center for Excellence in Developmental Disabilities Education,
Research and Service



Research Question:

- **What screening and referral trends exist among Connecticut pediatricians for toddlers suspected of having developmental delays, specifically Autism Spectrum Disorders; what components of clinical excellence can be identified, and what barriers to universal screening fall within these trends?**



What are Autism Spectrum Disorders (ASDs)?

- The National Institute of Environmental Health Sciences (NIEHS) classifies autism as a spectrum of disorders that impair an individual's ability to think, process emotions, develop language, and relate to other people (NIEHS, 2010).
- These deficits often translate to turbulent social interactions, altered verbal and nonverbal communications, and non-typical responses to sensory experiences such as restricted, repetitive, and stereotyped behavior (NIEHS, 2010; National Institute of Mental Health, 2010).



Autism . . .

without the proper support . . .

can be a source of exhaustion,
frustration, guilt, social isolation,
and financial ruin for the families of
affected children



Rita Schreffler declared:

- “Autism is a national health emergency. Our hope is that the government will finally declare it as such so that proper prevention, treatments and resources will be put in place.”



Is the Federal Government Listening?

- The U.S. Department of Health and Human Services' Office of Management and Budget lists under the division of Funding for Important Research:
 - “Supports Americans with Autism Spectrum Disorders”
 - allocation in fiscal year 2010 of \$211 million
 - treatment, screenings, public awareness, support services, and support for research to determine the causes and most effective treatments.



Centers for Disease Control and Prevention (CDC) 2009 statistics:

- estimate “an average of 1 in 110 children in the U.S. has an ASD”
- ASDs have been diagnosed in all racial, ethnic, and socioeconomic groups
- on average boys are 4 to 5 times more likely to be affected than girls

(CDC, 2010)



The Department of Health and Human Services has responded by adding a Healthy People 2020 objective:

Increase the percentage of young children with an Autism Spectrum Disorder (ASD) and other developmental delays who are screened, evaluated, and enrolled in early intervention services in a timely manner.

- a. Increase the percentage of young children who are screened for autism and other developmental delays at 18 and 24 months of age.
- b. Increase the proportion of children with an ASD with a first evaluation by 36 months of age.
- c. Increase the proportion of children with an ASD enrolled in special services by 48 months of age.



What does the Literature tell us?

- Multiple studies seeking to discover the cause of ASDs
 - Prevention
 - Possible cure?
- Sally Rogers, a psychologist at the Mind Institute of the University of California, Davis, and colleagues' RCT
 - **demonstrates toddlers with autism show dramatic improvement with early intervention** (*New Scientist*, 2009).
- Studies similar to the work of Itzchak and Zachor (2009) demonstrate
 - **with early intervention for very young children some can achieve reclassification of diagnoses**
 - **and the predictors of which children are likely to be reclassified can be identified** (*Research in Autism Spectrum Disorders*, 2009).



What's going on in Connecticut?

- Public Act 09-115, An Act Concerning Health Insurance Coverage for Autism Spectrum Disorders (formerly S.B. 301)
- effective as of January 1, 2010
- to assist families coping with autism by expanding group health insurance coverage for the diagnosis and treatment of autism spectrum disorders



Autism has . . .



Infiltrated our Society in Multiple Dimensions

- **The media**
- **Autism-based organizations**
- **The scientific community**
- **Laws**
- **Educational professionals**



What's a Family to do?

- More families than ever before are being touched by ASDs &
More concerned individuals are looking for answers . . .
- Many families are turning first to the internet, then to their pediatricians with current articles in hand and they need guidance to process this information (Trommer, 2009).

Are pediatricians



concerned that a diagnosis made too early will be one of haste?

- Eaves, Wingert, and Ho (2006) recommend
 - screening for ASD “should be as universal as possible”
- Stress
 - “importance of adequate specificity and sensitivity.”
- Caution
 - there is greater danger involved with false negatives (undetected ASDs) than with false positives at the prediagnostic screening stage
 - delay in diagnosis could mean a delay in treatment



As part of a 2006 revised policy statement the American Academy of Pediatrics (AAP):

- defined
 - **surveillance** as “the ongoing process of identifying children who may be at risk”
 - **screening** as “the use of standardized tools at specific intervals to support and refine the risk” (2007, p 1195).
- The AAP recommends scheduled screening for autism at 18 months and re-screening at 24 to 30 months of age (2007, p. 1198-1199).





AAP 2006 revised policy statement



- Current hallmarks for failing surveillance:
 - Concern by a parent
 - Concern by another caregiver
 - Concern by the pediatrician
 - Presence of a sibling with an ASD
- Presence of two or more is the general rule to initiate a formal evaluation
- This system assumes an ideal level of communication between the parents, caregivers, and pediatrician

(Trommer, 2009)

Universal screening safeguards against this margin of error!



Consideration of Risk Factors . . .

Are pediatricians including risk factors recently identified in the literature as part of their surveillance methodology?

- Study of 91 “ex-preemies” w/ birth weights less than 1500g
 - early autistic behaviors may be an under-recognized feature of VLBW infants
 - further suggest “early screening for signs of autism may be warranted in this high-risk population.” (Limperopoulos, Bassan, Sullivan, Soul, Robertson, Moore, Ringer, Volpe, & du Plessis, 2008)
- Who else is considered a potentially high risk aggregate?
 - Children living in poverty
 - Children who do not attend preschool or daycare
 - Children born to mothers greater than 40 years old



Are pediatricians comfortable with diagnosing and caring for children with ASD?

According to a 2009 study by Golnik, Ireland, & Borowsky the answer is no:

- “Primary care physicians report a lack of self-perceived competency, a desire for education, and a need for improvement in primary care for children with autism.”
- Despite AAP (2007) publication *New AAP Reports Help Pediatricians Identify and Manage Autism Earlier*
 - offered pragmatic information regarding early surveillance and screening
- Quick to follow clinical report: *Evaluation of Children with Autism Spectrum Disorders*
 - delineated clear algorithms and recommended guidelines (AAP, 2007).



AAP 2006 revised policy statement

- Conduct developmental **surveillance at all well child visits**
- **formal developmental screening** using a **standardized instrument**
 - at 9, 18, & 24 - 30 months of age
- Recommends **referral of 'at-risk' children**
(global developmental delays & ASDs)
 - to have detailed developmental & medical evaluation
 - AND early intervention services
- Simultaneously with statement release (**D-PIP**) :
Developmental Surveillance and Screening Policy Implementation Pilot
- Evaluate adherence of national sample of 17 diverse pediatric practices to these AAP recommendations
- Identify factors contributing to their successes and short-falls

(King, Tandon, Macias, Healy, Duncan, Swigonski, Skipper, & Lipkin, 2010)



Developmental Surveillance and Screening Policy Implementation Pilot (D-PIP)

- **Baseline survey collected**
 - on pre-participation surveillance
 - Screening
 - referral routines
- **All 17 practices attended a 1 day orientation workshop:**
 - New terminology
 - Available screening tools
 - Approaches to practice change
 - Data collection instruments
 - Methods of communication with payers
 - Collaboration with community-based programs
- **Each practice chose instruments to implement**



Developmental Surveillance and Screening Policy Implementation Pilot (D-PIP)

At completion of D-PIP

- “nearly all participating practices had successfully implemented AAP’s recommendations on developmental surveillance and screening”
- more children being screened for developmental delays
- but “many clinics chose not to implement certain AAP recommendations”
 - Resulted in a lack of consistent referral of all children suspected of having a developmental delay to early intervention programs
- An additional significant finding is that pediatricians found tracking referred children difficult

(King et al., 2010)



Project Purpose:

- Needs Assessment study - for quality improvement in response to trends in methodology of screening and referral among CT pediatricians for developmental delays and ASDs in toddlers
- Aims to assess the professional opinions and routine practices of CT pediatricians w/ emphasis on
 - potential barriers to universal screening of all toddlers
 - timely appropriate referrals per the AAP recommendations
- Results will be compared with D-PIP results evaluating fidelity of adherence to the AAP guidelines



Hypothesis:

- Barriers to universal screening of all toddlers for autism will be identified
- Current trends of surveillance, screening, and referral will be demonstrated to fall short of AAP recommendations and Healthy People 2020 goals
- CT will score within range of the baseline scores in the D-PIP study

Dates of Study:

Start Date: January 2, 2010

End Date: May 31, 2010



Methods:

Participants/ Recruitment/ Sample Size:

- Convenience sample of 800 CT pediatricians (Addresses provided by co-primary investigator, Robert Greenstein, M.D.)

Measures/ Instruments:

- Brief student-developed survey approved by co-PIs:
Mary Elizabeth Bruder, PhD. & Robert Greenstein, M.D.
- Paper surveys printed & sent to all CT pediatricians on mailing list
- Survey additionally accessible via Survey Monkey for participant convenience
 - Areas of demographics (brief), screening, referral, family support, legal, billing, and professional opinion explored through targeted questions



Methods continued:

Measures/ Instruments continued:

- an invitational letter requesting participation accompanied the survey
 - told no identifying info collected
 - told no way to identify participants by responses
 - told study results will be posted on the LEND website @
University of Connecticut A.J. Pappanikou Center for Excellence
in Developmental Disabilities: <http://www.uconnucedd.org/lend/>
 - link to online survey
- Second mailing sent 2 wks later
- Approximately 500 responses expected



Methods continued:

Data Collection Methods:

- Data collected by LEND fellows & staff via U.S. Postal Service & Survey Monkey
 - All files kept on a password protected computer and deleted by May 31, 2010

Analysis:

- All responses entered into SPSS software database file by LEND fellow
- Student project => descriptive statistics & potential correlations to be analyzed
- Results compared w/ results of D-PIP 2006 national pilot study



Results/ Expected Results:

- Expectation = areas of inconsistency will be identified within
 - trends in surveillance
 - screening methodology
 - Follow-up/ referral of toddlers with developmental delays specifically ASDs
- Expectation => similar barriers as those identified in the D-PIP study will also exist for CT pediatric practices.



Implications/ Conclusions/ Products:

- **Goal of project: to identify & break down barriers preventing universal screening**
 - to facilitate capture of more children who would benefit from immediate post-screening early intervention
 - to have a baseline against which to compare re-screening
- **This would be accomplished by informing CT pediatricians of the results of this study via the LEND website**
 - will highlight areas of concern
- **Posted with the survey results will be**
 - A list of resources specifically addressing areas of inconsistency revealed by the survey

(CTDSS, 2010)